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ABSTRACT

This handbook was produced to help Maine families of children with disabilities to deal positively with their situations and children. It provides insights into services that have been developed, problems that may arise, and resources available. The handbook discusses types of developmental disabilities; the role of parents as advocates; relationships with professionals; and procedures for getting help in such areas as diagnosis, vocational rehabilitation, due process, respite care, and financial assistance. Appendices contain directories of local and regional resources, a list of special education definitions, a glossary of acronyms, one reference, and one additional reading suggestion. (JDD)

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Insights

A Handbook for Parents of Children With Disabilities

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This chart shows some steps in a child's normal development. It shows at *about* what age children *do* certain things. Some children do things earlier or later, but most follow the steps in order.

months	A. Does he laugh or make happy noises? B. Does he turn his head to sounds?	A. Does he smile at you? B. Does he reach for familiar people or objects?
months	A. Does he "babble", repeat sounds together (i.e., mum-mum-mum)? B. Is he frightened by angry noise?	A. Does he stretch his arms out to be picked up? B. Does he show his likes and dislikes?
months	A. Does he understand "no-no", "bye-bye"? B. Will he imitate any sounds or words if you make them first?	A. Does he hold his own bottle? B. Does he play any nursery games ("peek-a-boo", "bye-bye")?
months	A. Does he have at least one meaningful word other than "mama", "dada"? B. Does he shake his head for "no"?	A. Does he cooperate in dressing? B. Does he come when you call him?
months	A. Does he have at least 6 real words besides his "jargon"? B. Does he point at what he wants?	A. Does he copy you in routine tasks (sweeping, dusting, etc.)? B. Does he play in the company of other children?
years	A. Does he talk in short (2-3 word) sentences? B. Does he use pronouns ("me", "you", "mine")?	A. Does he ask to be taken to the toilet? B. Does he play in the company of other children?
years	A. Does he use plurals or past tense? B. Does he use the word "I" correctly most of the time?	A. Does he tell his first and last name if asked? B. Does he get himself a drink without help?
years	A. Does he tell little stories about his experiences? B. Does he know his sex?	A. Does he share his toys? B. Does he play well with another child? Take turns?
years	A. Does he say a song or a poem from memory? B. Does he know all his colors?	A. Does he tell "tall tales" or "show off"? B. Does he play cooperatively with a small group of children?
years	A. Can he print his first name? B. Does he ever ask what a word means?	A. Is he a "mother's helper", likes to do things for you? B. Does he play competitive games and abide by the rules?

Credit–*Developmental Attainment Form for Children 0-5 Years. The John F. Kennedy Institute for Handicapped Children prepared in this form by David M. O'Hara, D.A.S.S. and Barbara Mosher, M.S.W., from an earlier version by Arnold J. Capute, M.D., M.P.H. and Robert F. Biehl, M.D., M.P.H.*

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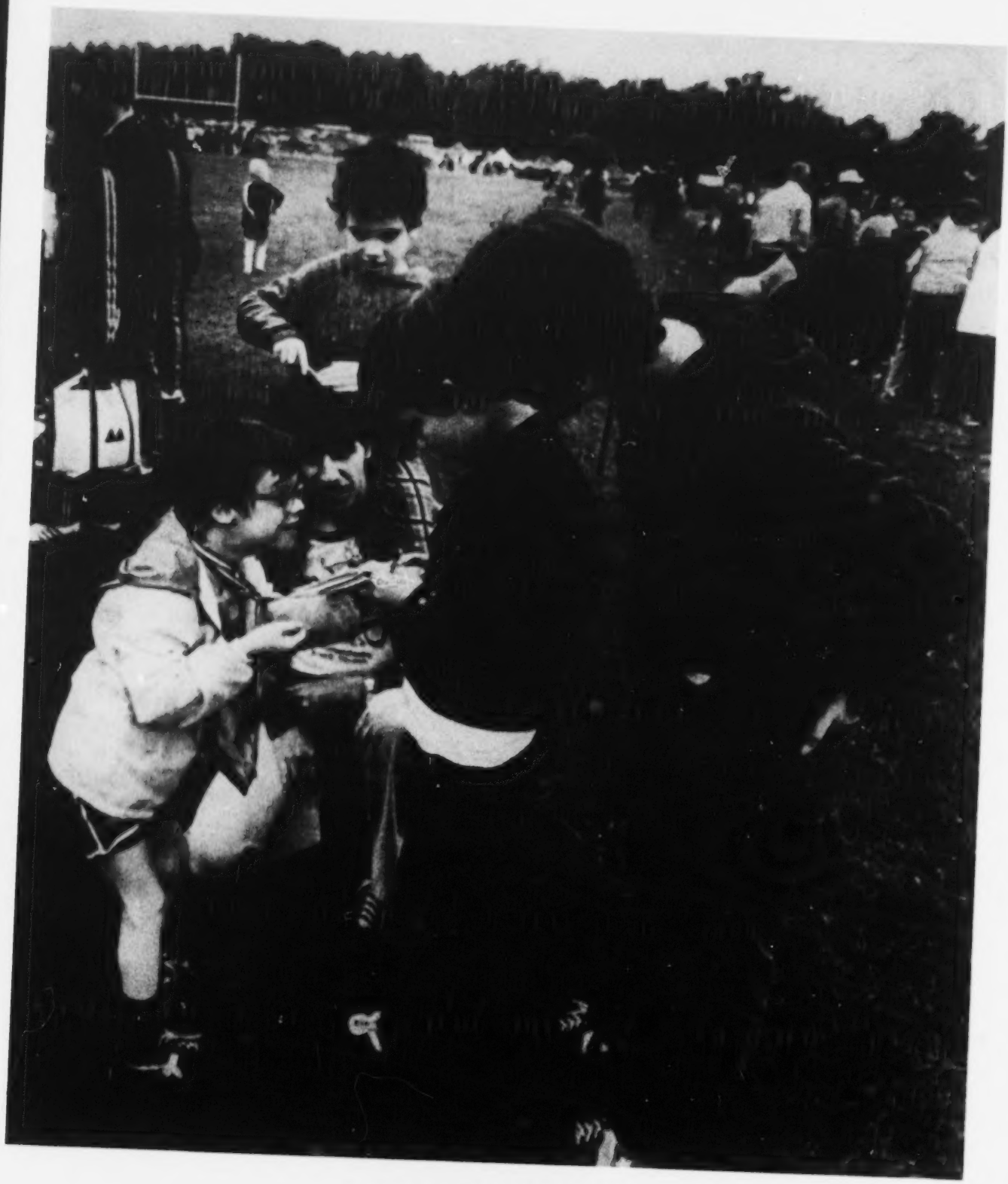

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Foreword

"There are problems with your child. He just doesn't seem to be developing as he should." These words, or similar ones, are heard at some point by every family of a child with disabilities. Whether a problem occurs at birth or at a later date, that time becomes a turning point for everyone involved. Ruth Shook, writing in *A Handicapped Child in the Family: Readings for Parents*, said, "I wanted someone to tell me exactly what to do, when to do it, and what the results would be. No one could do this. Only through talking with friends and other parents of children with handicaps, reading about similar problems faced by other families, learning more about myself and my child, sharing in the mutual support of my family, and making many mistakes, was I able to take a direction that was good for both of us."

This handbook has been produced with the help of many parents, friends and professionals involved with children with disabilities in an effort to help you and your family deal positively with this turning point and with your child.

Although you may at times feel confused and overwhelmed in the days and years ahead, you will soon discover the joy of living day by day with your child, knowing that you are shaping his future and helping him reach his fullest potential, whatever that may be. Do not dwell on what could or should have been. Think instead of what you have and what can be done today, tomorrow, next year. When you invest time, love and labor in your child, your reward will be an enriched life for both of you.

We have produced this handbook to provide you with insights into the services you may choose for your child, the problems which may arise and the resources which are available to you . You may find some sections of this book speak directly to you and others do not affect you at all. Topics which may seem uninteresting today may become important to you later. We hope you will keep this handbook and refer to it often as your child develops.

Lauret Crommett and Carol Boston, members, *Insights* Steering Committee and parents of young adults with disabilities.

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How to Use This Handbook

This handbook is about your child, your family, and developmental disabilities. Developmental disabilities are disabilities of many kinds. They may be very mild and even unseen, or they may be very severe and plain to see. The common bond among them is that they happen during the growing years of a child's life. They block, slow down, or change the normal course of development.

Families learn to meet the problems and needs caused by these disabilities. They also learn that not every need can or must be met at once.

This handbook can help. It is planned as both a beginning and an ongoing aid. It can be read all at once if you need a sense of what lies ahead, or it can be read in sections. It can be read over and over again.

Some parts of this handbook may apply to your specific problem; other parts may not. It does not try to list every phone number and service that can help you. But it can add insights and give you a sense of the many ways you can get support.

Please keep this handbook. Perhaps things do not make sense today, but at some point you may wish to have this handbook. If everything seems too much right now, put it aside and come back to it later.

Take one day at a time and eventually you will be ready to take those first steps. This handbook can serve as a road map for pointing you in the right direction.

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1. Beginnings: An Introduction To Developmental Disabilities

The birth of a child with a disability causes parents to examine many parts of their own lives. Many questions are raised. Finding answers to those questions may take a long time. This handbook will try to raise many of those questions, give some answers, and help you find others.

This handbook is one way of beginning. Its purpose is to:

- assure you that help is available,
- remind you that children with disabilities are more *like* other children than *unlike* them,
- define disabilities,
- explain some legal rights and resources,
- give some directions,
- show how parents can be the leading decision-makers in planning for a child with a disability.

The handbook has been designed to help parents with a child's special needs in various stages of living. Perhaps you have just received the information that your newborn is disabled. An obvious problem, determined at birth or shortly after, is agonizing; and you face many decisions, feelings, and changes.

Or your child may be older. You've thought for a long time that there is "something" wrong, that some stage in your child's life is slow in happening. Something is delayed. Once your suspicions and fears are confirmed, you can begin to breathe again. You can begin to act on your child's needs.

Whether your child is very young or is an older child, you face the giving up of a dream. All parents dream of having a "perfect baby." Sooner or later each must give up the dream. Those who have a child with a disability give up the dream sooner.

What lies ahead for you will be hard. You will have to make difficult decisions. Many agencies in Maine serve persons with disabilities in one way or another. You will often need to decide which services your child needs and then plan how to go about getting those services. The decisions you make will affect you and your family as well as your child with a disability You will need all the information you can get. Sometimes this will be confusing, and there will be times when you feel you cannot continue the day, much less face the future.

Many parents of children with disabilities are willing to reach out to you, to share their experiences and to help you with your child. They have organized groups to support each other and get the services their children need. They have the most to offer to parents such as you.

One important message from parents is that there are ways to reach your destination, if your goal is the best possible quality of life for you, your special child, and your entire family.

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If you can get over that [resentment] stage, then that's when your rewards come. If you can get past that and pull yourself up, and say, O.K. it's nobody's fault; I'm not going to blame myself any more. (English)

FOR PARENTS, WHOEVER YOU ARE

Many parents have written about the stages they went through when they learned about their child's disability. In the beginning they say they felt shocked. Of course they were not prepared for such news. Later, they felt very depressed and wanted to deny that there was a problem. This was an especially difficult period. Taking care of the baby was very difficult during this time.

One mother says:

Somehow, through all this, you wish you could find a warm cozy hole, crawl into it, and pull a lid after you. (English)

Parents say that even when they accept the fact that their child is disabled, it can be difficult because they resent families where there are healthy children. But slowly this feeling, too, passes and parents are able to accept their child with limitations. Another parent says:

If you can get over that [resentment] stage, then that's when your rewards come. If you can get past that and pull yourself up, and say, O.K., it's nobody's fault; I'm not going to blame myself any more. (English)

These feelings relate specifically to the birth of a child with a disability. But many feelings which you have on a day-to-day basis are ones which most parents share at times.

The whole range of feelings is normal and acceptable:

- defeat
- anger
- resentment
- disbelief
- sorrow
- weariness
- impatience
- inability to cope
- self-pity

These are hard feelings to deal with, but they can and do change. Parents need to remind themselves that their child's disability is not their fault. Often negative feelings will change to more positive ones if you recognize the feelings, and if you take some concrete steps to change either yourself or the situation. While negative feelings may recur, they are most often temporary. Parents of children with disabilities say, like all parents, they experience good feelings such as:

- acceptance
- hope
- determination
- joy in small successes
- pride
- satisfaction.

TODAY

There are some "immediates" no matter what your child's age and level of disability.

1. If you have just learned that your child is disabled, this is not the time to make a decision to send your child to an institution. Later on, that may be an alternative for some families, but it requires a long, complex decision-making process. Some of the material you read, and some doctors and counselors still state that this is the best way to handle the situation. Many young parents get strong pressure to send their child "away." You need to know much more about your child's possible options before making this decision. You will need strength to resist these pressures.

By far, the most important theme of the past twenty years in service for people with disabilities has been the movement to keep persons with disabilities in the community. Community-based services have been developed throughout Maine. Day care, foster care, respite care, small group homes and apartments are among them.

Right now, while your baby is new to this world, all he or she really needs is food, dry diapers, any necessary medical attention—and lots of warmth and security and love. Just like any other baby.
(Milligan and Trainer)

You want to look for options at this stage, not for quick answers to complicated problems. We are moving toward the idea that the most "normal" and "least restrictive effective environment" is best. Just do not be hasty in making long-term decisions.

2. Begin to talk with other parents.

No matter what or how severe the

disability, talking with those who have been there seems to be the main line of information, support, encouragement, and understanding. If you do not know who other parents are, organizations working with major disabilities are listed in section 2 of this handbook. These groups can usually put you in touch with other parents.

One of the important changes in the past few years is that parents are no longer expected to "be brave" or "do it alone." They can and should ask for and use the help of others.

3. Find out where your child is at *present* and start there.

Nothing you read or hear about your child's problem is "cast in concrete." If your child is very young, detailed testing may be impossible. Some developmental disabilities, like autism, are very difficult to diagnose. There are constant changes in research, services, and legislation.

All of these changes may help your child's future. It is important to get started no matter how much you, the doctor or other professionals know about the problem.

4. Take a first step.

If your child is only a tiny baby, he or she can begin immediately in an infant stimulation program. Most parents have found that to begin a positive action program brings relief. It gives a sense of helping their child and themselves. Parents of young children who are delayed in their development should not wait to get help. Even if an exact diagnosis is not complete, starting early treatment can reduce later problems.

5. Try to get as much information as you can about your child's disability.

The more you know about your child's problem, the better. This handbook includes brief descriptions of some disabilities. But by no means are they complete. There is much more to know.

Authors and experts do not all agree. Neither will the people you and your child encounter. You will more than likely hear different points of view and will need to make up your own mind.

A word of warning—because things have changed in the last ten years in the field of helping the child with a disability, try to get the most recent books and brochures on a topic. It may be that no one knows exactly what your child's problem is. But you can still get useful information on how to treat your child, regardless of the diagnosis.

6. Think of how you will divide your time and energy among other family members.

The needs of your child with a disability can quickly overshadow the needs of other family members. It is a hard job for any family to learn to balance everyone's needs and skills. It will require a lot of thought and planning.

Parents need time for themselves. Brothers and sisters who are not disabled need some undivided attention from their parents. Sometimes in the eagerness to help a child with a disability, other

Parents, like children, come in all sizes, shapes, and stages.

Perhaps you are one of these:

A FIRST-TIME PARENT—you face the needs of a child with a disability, but you may not know about the usual growth of a child without a disability. You may feel very unsure.

A SINGLE PARENT—you may be young, even a teenager, or you may be divorced or widowed. You may feel very alone.

A PAIR OF PARENTS—you may share a readiness to manage your family's special needs, or it may be that one or the other is not willing or able to take part.

AN UNREADY PARENT—you may perceive so many problems that you feel overwhelmed. It may take months to face these new challenges.

A CONFIDENT PARENT—you may be used to taking charge and making decisions like the ones which lie ahead. Not many parents (or people in general) are able to do this. Fortunately, those few are often able and willing to reach out to others.

Right now, while your baby is new to this world, all he or she really needs is food, dry diapers, any necessary medical attention—and lots of warmth and security and love. Just like any other baby. (Milligan and Trainer)

children can be overlooked. Brothers and sisters may have many special concerns. Sometimes they may be expected to assume too much of the family responsibility. They can feel pushed aside. Later, they will need to know whether they might also have a child with a disability. They may need to be reminded of the facts about the disability. It takes a lot of planning to figure out how everyone's needs can best be met.

One step is to identify a reliable babysitter, respite program, friend, or family member who can give the family time away from the member with a disability. Some families also realize they require counseling to help resolve their conflicts. Some resources are included in the section called "Next Steps."

7. Think how you will talk with your relatives and friends.

Coping with others may seem impossible. Some of this handbook's resources may help. You may need to "bend over backwards" to help grandparents, aunts, uncles and especially brothers and sisters at a time when you yourself are troubled. Occasionally, some relatives and friends may never accept your child. You may feel very sad and unhappy about their rejection. But remember, it really is their problem, not yours. Often, given a chance, family and friends can be your best support system.

TOMORROW

Parents can be glad that they are living in the present decade. There have been great changes in attitudes, services, and skills in serving people with disabilities in the past several years. There is an emphasis on what people can do rather than what they cannot do.

Strengths and abilities are considered, along with weaknesses and limitations. Parents no longer hide themselves or their children. Parents believe that they have the right and the responsibility to get help for their child.

Much of this change has come about because parents have led the way. Realizing the needs and the worth of their children with disabilities, they became determined to win for them relief from the stigma of disabilities. They worked for recognition of their child's legal rights and for opportunities to develop every ability as far as possible. Parents no longer assume that their child cannot grow or cannot change.

Above all, as you proceed to read this handbook, it is important to keep in mind that there are more similarities than differences between children who have disabilities and those who do not. A child with disabilities is a *child* first and has all the needs of any child:

- physical and emotional care
- stimulation of his senses and body
- education
- recreation, sports, and play
- medical care
- social opportunities
- legal resources and protection
- independence and self-sufficiency
- and *especially* love, affection, and acceptance as a real person.

Pleasure in a child's growth and pride in your personal ability to meet problems are important. Many parents relate good feelings. A mother talks about the feelings of parents:

> *Don't ever put yourself down as a person. This is, I think, where the young people [hurt themselves] — maybe it's the blame they feel, but don't ever put yourself down. It just takes a lot of guts to get out there and do it. But that shows what kind of person you can be, and that's important to you. (English)*

And the parent of a boy with muscular dystrophy wrote:

> *During one of our trips to the beach, David learned a skill which might be considered quite simple for most people. However, for him it was one of the greatest accomplishments of his young life when he learned to float alone. Yes, this youngster who could not even feed himself learned to float without aid. At last he could do something that no one else in his family could do. Imagine the thrill this gave him, and even more, imagine the thrill it gave his family. (Strickland)*

Getting the right care or programs for your child will be hard work. Disabilities are often hard to pinpoint. There may be many dif-

Don't ever put yourself down as a person. This is, I think, where the young people [hurt themselves]—maybe it's the blame they feel, but don't ever put yourself down. It just takes a lot of guts to get out there and do it. But that shows what kind of person you can be, and that's important to you. (English)

ferent aspects to the problem. Even people who work in the disabilities field sometimes find it difficult to get the proper information. Perhaps you will have to write many letters and make telephone calls. There will be rewards. You will help your child, and in the process, may help many others.

One mother writes of her child with Down Syndrome:

> *These children respond to love and attention like flowers in the sun. Many can learn—to a limited degree—but learn nevertheless. Ben himself has helped us to 'adjust.' His sense of fun is tremendous... he will do anything for a laugh... and when he smiles, he throws his whole small self into it. We look at our three older children with love and pride in their intelligence, abilities, their achievements. With Ben, we feel a very special love and pride. (Milligan and Trainer)*

FROM PARENTS: QUESTIONS YOU CAN AND SHOULD ASK

Sometimes defining the questions is the hardest step. Knowing what and whom to ask is another step. Here are some questions some parents have felt are important:

- What is my child's disability or combination of disabilities?
- What kinds of treatment and options are there for this disability?
- What caused this disability?
- Will future children in the family have this disability?
- What do I do first and who can help me decide what is best?
- Are there special programs for all ages?
- How are children placed in special programs?
- How can I be sure these programs are right for my child?
- What about my family's needs?

  Brothers/Sisters
  Social needs
  Recreation
  Rest
  Religious training
  Money and cost

The rest of this handbook is designed to help you get answers to these questions.

First, there is a section about disabilities. This section describes some disabling conditions. It lists some of the primary organizations related to each disability.

Next you will read a section about your human and legal rights and some related responsibilities. There are some things your child is entitled to by law. Following the discussion about rights is a section about the relationship between parents and professionals.

Finally, there is a section on services for children with special needs. Getting proper services is always the hardest, most time-consuming task for parents. There is a description and discussion of some of the many kinds of help which are available in Maine.

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2. A Developmental Disability is . . . One or Many Disabilities

A developmental disability is a mental, physical, or emotional condition which affects the development of an individual. It slows or lessens a person's ability to do certain things that are expected of most adults, such as taking care of personal needs, graduating from high school, getting a job, or raising children. The disability occurs before the age of 22 and is expected to last for a lifetime.

The federal legislation which defines a developmental disability states that the person's ability to carry out certain major life activities must be affected. The activities are defined as:

- self care
- learning
- mobility
- self-direction
- economic sufficiency
- use of receptive and expressive language
- capacity for independent living.

The disabled person must be affected in three of the areas listed. Also, the disability must require special treatment, given by many people, which will extend over a lifetime.

In addition to the federal legislation, there is legislation in Maine which defines disabilities for purposes of educational services (Maine Public Laws, Chapter 693, 1982). Handicapped children are those who may require short or long-term special educational services. The problem may be related to learning difficulties, emotional, or physical factors. The general education programs cannot provide enough help to insure that these children develop to meet their potential. The definition of handicapped from P.L. Chapter 693 will be found at the end of the handbook. Lists of disabilities which are included in the definition of handicaps are also included in the Appendix.

TYPES OF DISABLING CONDITIONS

There are many problems which are considered developmental disabilities.

The first laws assuring service to persons with disabilities included only four problems: mental retardation, autism, cerebral palsy, and epilepsy. In 1978, the law was changed. Now based on a person's inability to do certain tasks, it covers many problems and developmental delays. Services must be provided for disabilities in three large areas:

- physical
- mental
- emotional.

Sometimes a child has more than one problem. Multiple disabilities may be present, affecting more than one area such as:

- mental and physical
- emotional and mental
- physical and emotional.

There can be short-term problems as children grow and learn to live daily lives with disabilities. Children with mental retardation may develop some emotional concerns as they become part of larger groups. Often they and their families need some mental health counseling. A child with cerebral palsy may need special help in learning techniques of communication. A child without sight or hearing may experience emotional frustrations that need special help. Some children with Down Syndrome have heart or respiratory problems.

In considering types of disabling conditions, it is also important to keep in mind that no two children are alike. Just as children who are not disabled are different from each other, so each child with disabilities is unique. For example, although children with Down Syndrome look similar (a typical type of facial feature), they vary in intelligence and abilities. Having the characteristics of Down Syndrome has nothing to do with achieving in society. Each child deserves an assessment and treatment program which will help him develop his own capabilities.

An important first task for parents is to know something about the many possible disabilities. Here are brief descriptions of the kinds of disabilities your child might have. These are very general descriptions to serve as guidelines.

PHYSICAL IMPAIRMENTS

This category includes many physical problems which may put severe limitations on a child's participation in school, family, and social

life. It may include an impairment with which the child was born, a birth injury, or something caused by a disease or accident. One example of a physical disability which is inherited is osteogenesis imperfecta. This is also known as brittle bone disease. Other physical disabilities might include cleft palate, club foot, or the lack of upper and lower extremities.

For purpose of educational services, the Maine law provides special services for children because of impairments in one or more of the following: vision, hearing, speech and language, cerebral or perceptual functions, behavior, or mental development or maturation.

These problems vary in severity and require different types of treatment.

EPILEPSY

Epilepsy refers to a problem with the nervous system. People with this problem often have seizures. These seizures can be very mild or very severe. For example, in a mild seizure the child may twitch slightly or his or her eyes might go blank. In a severe seizure, the whole body can shake violently. There is irregular breathing, drooling, and sometimes loss of control over the bladder. In many instances, doctors never really discover what causes the epilepsy, but they are often able to control seizures with drugs.

CEREBRAL PALSY

Cerebral palsy refers to many conditions which relate to problems with the muscles. These conditions involve the brain (cerebral) and muscle control (palsy). Usually some damage has occurred to the part of the brain which controls the muscles. Persons with cerebral palsy may have a slightly awkward way of walking or speaking. Sometimes their arms and legs move in ways that seem out of control. With some people, even though part of the brain is damaged, the rest of the brain functions well. They can think and learn normally. But for others, another part of the brain may be injured. They may also be retarded or have hearing and visual problems. This condition is referred to as a multiple disability.

Again, doctors do not always know what causes cerebral palsy. It could have resulted from an injury during birth or from an infection. Poor health of the mother could have caused it. Sometimes young children swallow lead paint, and their nervous system is affected.

Surgery can correct some of the problems. A recent development in medical research is a delicate but often effective brain operation which has been performed in a limited number of cases. Many new medicines are now available. Sometimes physical therapy can improve muscle control. Also, braces can be used to assist the child in controlling movement.

SPINA BIFIDA

Spina bifida is often called open spine. The scientific name is myelomeningocele. This is a problem immediately obvious at birth. It is a problem of the central nervous system. The bones in the spine do not close or are only partially closed. Some of the membranes, nerves or part of the spinal cord come out and form a type of sac, usually near the lower back. Sometimes this causes excess fluid in the brain or other problems of the feet, legs, or hips. The baby may lack sensation in the lower body. There is often limited or no bladder or bowel control.

Doctors do not know why the problem occurs. Surgery to close the open area is usually required and possible within the first day of life. This provides protection against infection. It begins the process of repairing defects. A tube or shunt may be surgically placed to remove extra fluid that can collect around the brain. Braces can often help a child walk.

MENTAL RETARDATION

Mental retardation is not mental illness. It is not a disease which can be cured. It is likely to be a lifelong condition. The child with mental retardation is one who develops more slowly and has special difficulty in learning.

There are different degrees of retardation. Some individuals have more limitations than others. For those children who are significantly retarded, even simple tasks may sometimes seem very difficult.

There are over 200 known causes of mental retardation. Sometimes

Mental retardation is not mental illness. It is not a disease which can be cured. It is likely to be a life-long condition. A child with mental retardation is one who develops more slowly and has special difficulty in learning.

the child is injured at birth. Sometimes the mother becomes ill during pregnancy, for example, with German measles. Sometimes something happens to the genes or the material in the cell which gives messages about the make-up of the child. Often there is no easy answer as to what caused the child's retardation.

Down Syndrome is the name of one form of mental retardation. Down Syndrome, which is present at birth, is caused by a change in the body cells. Often there will be heart or breathing problems.

Children with Down Syndrome vary as widely in abilities as do all children. Both parents and professionals often describe them as warm, loving, happy, and willing to learn. However, they learn very slowly and reach limits early. Parents of children with Down Syndrome will want to start them in special programs as early as possible. Information about these programs is in Section 6.

Even though a child is mentally retarded, he can grow and develop. Infant stimulation developmental training programs can greatly improve a child's ability to take care of him or herself, to learn, and to develop social skills. These children can lead useful adult lives.

LEARNING DISABILITIES

A learning disability is a problem with understanding and using written or spoken language. The child's ability to learn, remember, follow directions, speak, write, spell, or do math problems is affected. Most often this child has average or above average intelligence. Public Law 94-142 states that *the term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, or emotional disturbance, or of environmental, cultural, or economic disadvantage.*

Learning disabilities are often difficult to diagnose. They are sometimes called the invisible disability. Many children with these hard to define problems develop behavior problems and become disruptive or school dropouts. One or more of these signs may warn parents to look for help: if a child

- is failing in reading, spelling, writing or arithmetic while teachers insist he could do it if he tried;
- is poorly coordinated, clumsy, awkward, has difficulty in writing, tying shoes, catching balls;
- is confused in language, speech, following directions;
- is usually forgetful, inattentive;
- is easily distracted, impulsive, overactive, or overly quiet.

There is no known cause of the learning problems. Once your child has been evaluated, a special learning program can be developed to help him improve or overcome these problems. Most children with learning disabilities can achieve their potential with proper help.

The Association of Learning Disabilities says that children with these problems need:

- early discovery
- correct diagnosis
- special educational, medical, psychological, and social services.

AUTISM

Autism is a problem with the mental or emotional development of a child. It also seems to be related to the central nervous system.

No one knows exactly what part of the nervous system is affected. Some research points to damage in the part of the brain which controls language and information gathered from the outside world. There is some evidence that some body chemical imbalances may be part of the cause of autism.

Usually the child with autism is withdrawn. As infants these children often do not respond to being picked up or cuddled. Because of this lack of response, sometimes the children may seem mentally retarded. The child may move his body in very mechanical ways, like a robot. Some children do not speak nor respond to noises or light. Their patterns of play are unusual. They may spin tops or flap their hands for hours at a time.

Often doctors define the problem in very different ways. Some state the child is brain damaged, psychotic, schizophrenic, or emotionally disturbed. This lack of definition is a very real problem

in treating autism and is very frustrating to families. Parents are still sometimes blamed for causing autism. This is not true.

There is no known cure, but there are different treatment programs which help. Most are educational programs which teach the child to speak, to take care of personal needs, and to behave in socially acceptable ways.

EMOTIONAL DISTURBANCES

A child with an emotional disturbance is one who is experiencing emotional problems to the extent that his ability to get along at school and at home is seriously affected. He or she may be extremely depressed or have an extreme fear of school. Some children become aggressive. This child might be very withdrawn and unable to relate to family or peers. There is limited knowledge of the exact causes of emotional disturbances. However, treatment can be effective. Psychiatric therapy, counseling, and, in some instances, medicines, can produce improvements in behavior. Again, in order to be considered developmentally disabled, the child must be affected in the ways described earlier. There must be impairment of his or her learning, self-direction, self-care, or capacity for independent living. The developmental disabilities laws are just beginning to define the services needed for children with severe emotional disturbances.

DEVELOPMENTAL DELAYS

Developmentally delayed is a term often used when a child does not seem to be growing and changing according to expected steps. A child can be delayed in several, often overlapping areas. These areas are body movements, speech and hearing, self-care, response to other people, ability to behave, and ability to follow directions. Often the causes and extent of delay are difficult to diagnose.

There are many stages in a child's growth. These are described on the front and back inside covers of this handbook. These stages are predictable and occur at about the same age in most children. Certain activities like grasping or reaching for a toy, following a light with the eyes, making sounds, and crawling on all fours may show how well or quickly a baby is developing. When these actions and skills do not seem to happen at the expected age, parents should begin to ask questions. Most likely there is nothing wrong, but perhaps there is a reason to be concerned and to get help in infancy or early childhood.

Often the term developmental delay alerts parents to watch closely as a child grows. They can be in contact with providers when there are questions and concerns. Since parents usually know their child best, they can often recognize needs early and get help.

Most areas of Maine now have programs designed to stimulate a young child to develop new skills and abilities. These programs are provided through schools, health agencies, centers such as cerebral

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palsy centers and associations for retarded citizens, hospitals and at home.

FETAL ALCOHOL EFFECTS

Fetal Alcohol Syndrome and Fetal Alcohol Effects are caused by a woman consuming alcohol while pregnant. Fetal Alcohol Effects may include mental retardation, bone deformities, cleft palate and heart defects. Children with Fetal Alcohol Syndrome can be detected by characteristic facial features, but children with Fetal Alcohol Effects are more difficult to diagnose because their problems are less severe and they may have no visible disability.

PARENTS CAN HELP— ASSOCIATIONS FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES IN MAINE

There is no way to know the exact number of families who have a member with a disability. This is especially true when the disability is defined by a person's inability to carry out certain activities rather than by a medical label. For example, it may be easier to count the number of individuals who have cerebral palsy than it is to count people with disabilities who have problems finding a job or finding an apartment or using public transportation.

Many other people have shared the frustrations and problems which you now face. Parents of children with disabilities have come together to share those experiences and offer support to each other. Even though your child's diagnosis may not specifically identify a disability, he may be developmentally delayed. The members of parent organizations may be able to help you in finding services. Many of these parents are willing to help you and your child. Refer to the listing below for the names and phone numbers of the groups you might call.

ASSOCIATIONS FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

Maine Association for Handicapped Persons
P.O. Box 998
236 Oxford Street
Portland, Maine 04104
774-4360/1-800-492-0730

Pine Tree Epilepsy Association
622 Congress Street
Portland, ME 04101
772-7847

United Cerebral Palsy of Northeastern Maine
103 Texas Avenue
Bangor, ME 04401
941-2885

Cerebral Palsy Center
331 Veranda Street
Portland, ME 04103
874-1125

Maine Head Injury Foundation
P.O. Box 5415
Augusta, ME 04330
626-0022

Mid State United Cerebral Palsy
273 Capitol Street Extension
Augusta, ME 04330
626-3497

Muscular Distrophy Association of America, Inc.
622 Congress Street
Portland, ME 04101
772-5418

Cystic Fibrosis Foundation
142 High Street, Suite 421
Portland, ME 04101
773-0133

Maine State Alliance for the Mentally Ill
P.O. Box 5057
Augusta, ME 04330
622-5767

Pine Tree Society for Handicapped Children and Adults
84 Front Street
Bath, ME 04530
443-3341

March of Dimes
P.O. Box 68, 12 Acme Road
Brewer, ME 04412
989-3376

Special-needs Parent Information Network
P.O. Box 2067
Augusta, ME 04330
582-2504/1-800-325-0220

Regional offices of the Bureaus of Children with Special Needs and Mental Retardation, community mental health centers, and the Department of Human Services are in the Appendix.

For additional information on groups serving individuals with disabilities, contact the Maine Planning and Advisory Council on Developmental Disabilities.

3. Parents as Advocates

You, as the parent of a child with a disability are the natural advocate for your child. One parent has said, "You can't be too involved!"

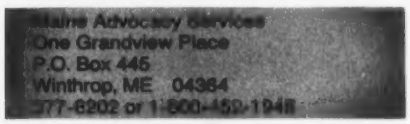
YOUR CHILD'S ADVOCATE

You are your child's best advocate. You will need to be informed. You will need to be assertive.

Sometimes even with our laws, individuals with disabilities and their families need to defend their rights to receive appropriate services. Sometimes families want other helping persons to be involved and to give extra support. This help may come from friends or it may be obtained through the Advocates for the Developmentally Disabled.

There are many steps you can take if you feel your child is not being treated equally. These steps may include complaints to appropriate boards, appeals, and grievance procedures. If you still are not satisfied, you may require legal assistance.

In Maine, if you need any legal or advocacy help, call:



YOUR CHILD'S RIGHTS

An advocate is one who supports the rights and needs of persons unable to do it for themselves. You, as the parent of a child with a disability, are the natural advocate for your child. One parent has said, "You can't be too involved! You are your child's only advocate." While there are others who certainly will aid in protecting the human and legal rights of your child, in the long run you are the primary advocate.

To be an advocate you should be informed. This handbook will provide some of that information. You will need to get additional information and this handbook will help you in doing that. In raising your child, you may also be required to behave differently. You may need to be much more assertive which may take practice. This handbook will help you take some steps in becoming more assertive. Someday you may require legal assistance to help you protect the rights of your child. Sources of legal assistance are discussed here.

There are two kinds of rights: human rights and legal rights. Human rights are basic. It is the belief in the United States that all human beings are entitled to certain basic freedoms. Many of these rights are spelled out in the Constitution. Human rights are reaffirmed for citizens with disabilities in many different documents, for example, the United Nations Declaration on the Rights of Mentally Retarded Persons, 1971.

Legal rights are those human rights protected by law. In order to assure that basic rights are guaranteed, laws are passed which define the specific ways special groups will receive programs, services, accessibility, and representation.

BASIC RIGHTS

The following are some of the basic rights of citizens with disabilities:

- *The Right to an Education* in the least restrictive environment or the right of every child to reach his highest potential. This learning process should happen in ways as close as possible to the activities and patterns of everyday life and regular schools.
- *The Right to a Care Plan* or the right of each person with disabilities whether in the community or in an institution to a well-designed written plan for his/her ongoing care.
- *The Right to Trained Qualified Staff* or the right to receive services from individuals who have the proper training and experience to administer and provide programs and services necessary for children with disabilities.
- *The Right to Access to Records* or the right to have records which are current and have correct information. The records should be kept private. All agencies should recognize the parents' rights to review and copy a child's records. Public school records are open to parents.
- *The Right to Advocacy* or the right to have one's legal and human rights represented and to receive legal counseling and advice.
- *The Right to Informed Consent* or the right of a person with disabilities or his or her guardian to understand what is involved in a decision. The individual knows what the choices are and can make a decision based on the information that is given. The individual voluntarily agrees to treatment or to take part in any research.

• *The Right to Freedom from Involuntary Servitude* or the right to be free from performing labor against one's will and that, if work is performed by choice, fair wages will be paid.

• *The Right to Payment for Care* or the right to receive needed care and treatment if you are not able to pay.

• *The Right to Equal Housing Opportunity* or the right to rent housing on an equal basis with persons who do not have disabilities. In other words, a landlord cannot refuse to rent on the basis of a disability only.

• *The Right to Equal Access to Buildings* or the right to physical access to all buildings or facilities financed with *public* funds.

LEGAL RIGHTS

Legislation which names the specific rights of citizens with disabilities has been passed both in Maine and by the United States Congress. The most current federal law was passed in the fall of 1987. It is known as Public Law (P.L.) 100-146. Support is given to relocating people now in large institutions and keeping others from entering them. Special efforts will be made to have people with disabilities remain in their own homes and communities, learn, work, and live as normally as possible. Most will require some services. Some will require many services. Some will require total care. The law makes clear that services must be given.

Before this law there were several others. Their names and numbers will become part of your thinking. You will want to remember them. They effect all parts of the lives of people with disabilities

• Public Law 95-602—Rehabilitation, Comprehensive Services and Developmental Disabilities Legislation

• Public Law 93-112, Title 5, Section 504—The Rehabilitation Act of 1973, usually known as the Rehab. Act or simply Section 504

• Public Law 94-142—Education for All Handicapped

• Public Law 99-457—Education of the Handicapped Amendments of 1986

• Maine Public Laws Chapter 693, 1982—AN ACT to Revise the Education Laws

The Developmental Disabilities Act and its amendments define developmental disabilities and services required for them. Included is a requirement that every state have a protection and advocacy system. There are many problems which may be dealt with by such a system: employment discrimination, rights to education, transportation and building accessibility, guardianship, adult protective services, relocation of people from institutions, and rights of people in institutions. Support and technical aid is given to individuals and groups that work with people with disabilities and their needs.

This aid can include discussion of issues, going to court to enforce laws, public hearings, and coordination of services. It can mean helping people learn to be their own advocates or serve as advocates for someone else. Services like this are given free of charge.

Under Section 504 any public or private building or service which uses public tax dollars must be accessible to citizens with disabilities. Service must be made available and physical barriers must be eliminated. All public transportation must make service usable by people with disabilities. Examples of accessible facilities include lowered telephones and water fountains, street and building ramps, Braille and picture signs, convenient bus seating, and wide entries to restrooms.

Public Law 94-142 and PL 99-457 guarantee a free, appropriate public education for children with disabilities from age 3 to 21. These laws:

• require that states provide special education and related services to children with special needs.

• provide financial assistance to states and local school districts to provide appropriate programs and services.

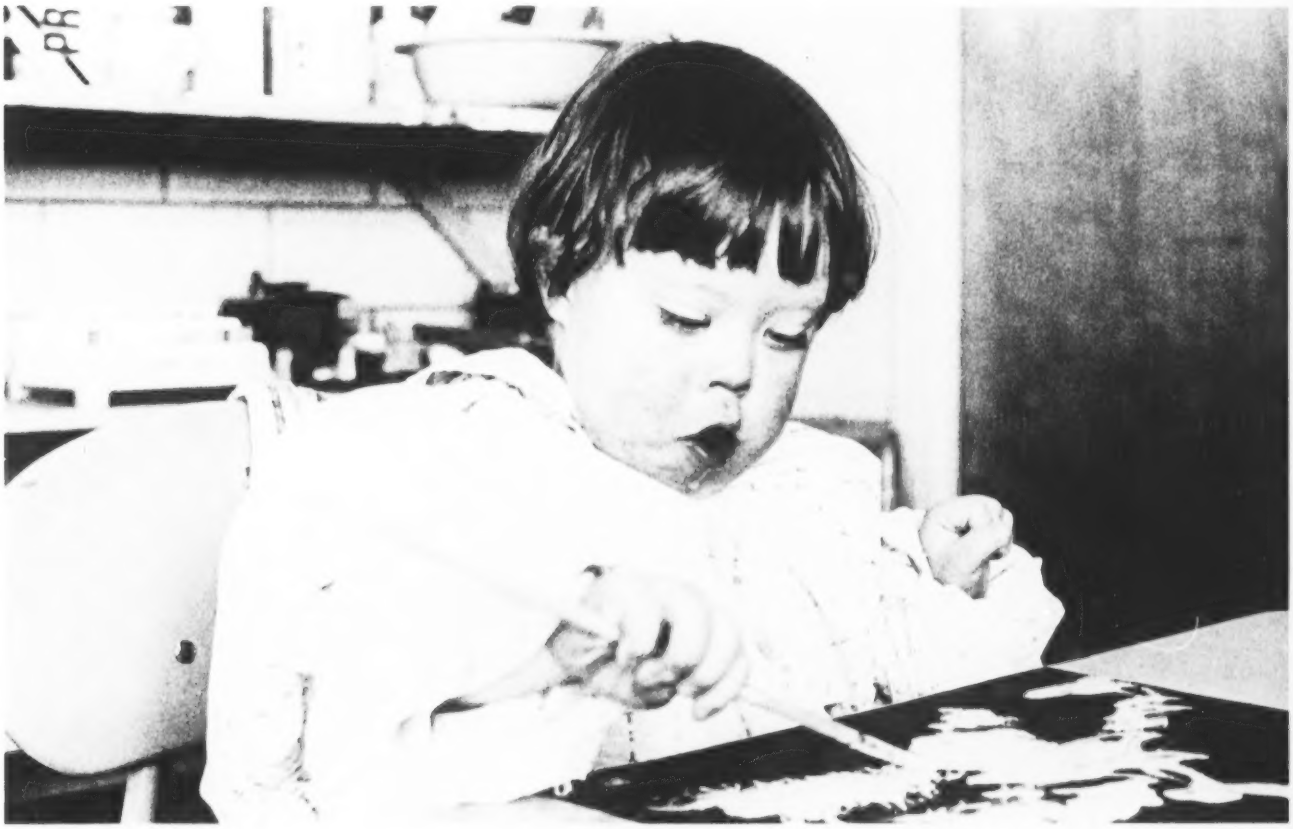
• establish and protect due process for parents and other advocates. These laws are discussed further in Section 6 of this handbook.

Maine P.L. Chapter 693 describes the disabilities which are covered under Maine law. The law discusses special education services which the State must provide and procedures which must be followed. It describes how parents should be involved. The

definitions of handicaps stated in the Maine law are found in the Appendix of this handbook.

Sixteen pre-school coordination programs now operate in Maine, coordinating the services of public and private agencies to preschool children with special needs in each program's geographic area.

Originally established to serve children with disabilities from ages three to five, the 0 to 5 coordination sites now provide information and referral services for children and their families from birth. The sites vary in the extent of services provided, but they will be the major component of Maine's compliance with PL 99-457, which mandates the services and rights which children from five to twenty received under PL 94-142 be provided to children with disabilities from age three and expands the state's ability to serve children from birth.



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4. Parents and Professionals

In raising a child with a handicap, most parents will meet a large number and many kinds of professionals—physicians, psychologists, teachers, social workers and others. Some will be helpful and others will not. Likewise, professionals who work with the handicapped child will meet a large number and many kinds of parents. Some will be informed and helpful; others will not. It seems safe to say, however, that the quality and quantity of help and support the ***child*** *gets will rest on the ability of the parent and professional to work well with each other. Parents are usually the people who know their child best. The professional should respect and use that knowledge. The professional is usually an expert in his field. It should be part of his responsibility to give insights and information to the parent. And both should keep in mind that is the* ***parent*** *who must lead his child through the many services he will need in growing up. The more information and understanding the parent gets from the professional the better the job he will do. (Morton)*

Parents and professionals need to respect each other. They must learn to work together. More and more often, services for children with disabilities are being planned and carried out by groups or teams of specialists. There are entire centers for diagnosing the needs of children. Many times teachers, social workers, reading or hearing or speech specialists plan together for a child's care. Some of this joint planning is set by law. The hope is that this planning results in better care for children. Follow-up to see that treatment is carried out is also required.

Parents have not always been included in this joint planning. Often they did not feel capable of being included. Many times professionals were not willing to treat parents as if they knew anything. Sometimes meeting together led to bad feelings of being "put down" or threatened. There could be anger or the need to protect an idea or frustration at the inability to understand each other. Parents were afraid to ask questions. Professionals often could not or would not answer them. Many doctors for example have been expected to "cure." But many disabilities are not curable.

Added to this distrust was the difficulty of getting everyone to work together. A child could be getting help from many places. Just setting up visits and meetings takes time. Making sure each person involved knows what the other is doing and saying is hard.

Someone had to be in charge. Some laws began to insist that parents be included in all planning and decisions. Some professionals began to realize they did not always know about the rest of a child's life and could no longer take full charge. Parents began to realize that for practical reasons they were the best persons to be in charge. In fact many parents had been doing this—getting children into programs, getting new programs, insisting their children had the right to a good life.

Words like "primary case manager" or "monitor" or "coordinator" have come into use. These words mean the person with the job of putting—or pulling—the pieces of care together. More and more often that person is the parent. Sometimes parents who want to do this job have experienced resistance. Change is not easy and takes time. But both parents and professionals can learn and change.

Nicholas Hobbs has written a book called *The Futures of Children.* He gives two lists of suggestions—one for parents, one for professionals. Those lists may help you know what to expect and get from yourself and professionals.

Some of the ideas for parents are:

- You are the primary helper, the expert on your own child.
- Your best tool is not an angry approach. Part of your job will be gentle persuasion. Stay cool. But insist on your right to be included.
- Read. Learn as much as you can.
- Talk freely with professionals and other parents.
- Stay in close touch with your child's teacher.
- Listen to your child. It is his point of view that he is giving to you; on that, he is an expert.
- Work hard at living the idea that differences are fine. Your child

Parents and professionals need to respect each other. They must learn to work together. More and more often, services for children with disabilities are being planned and carried out by groups or teams of specialists.

will learn most from your example.

For professionals:

- Have the parent involved in everything.
- Help make daily living plans for the child based on the family's and child's life.
- Find out about community services of all kinds.
- Keep your talk and written reports clear and jargon free. Give copies of anything written to the parent.
- Make clear that there is *no* unchanging, "one-shot" diagnosis. Stay away from labels.
- Help the parent think of the child with a disability like any other child.
- Be sure the parent knows his child's abilities and strengths. Help the parent respect his child. There is no place for blame or fault.

Many parents feel that their best support is a professional who:

- listens
- knows about resources
- becomes involved with the whole family
- develops an overall view of their needs
- helps them coordinate needs and services.

One parent has said that providers do not have the right to make decisions for parents. Give options and plans, yes. Help parents to learn to make decisions, but do not make those decisions for them.

Who's in charge here? You are, and you are about to begin a journey.

A CHECKLIST FOR PARENTS

Many parents have reported that their first important step was to learn to manage information. Many said they learned this years too late. Here is a checklist from those parents of things you can do:

- ☐ Collect and save copies of records. Make and save copies of all your letters to and from officials—doctors, psychologists, school staff, Social Security personnel—anyone who is involved with your child's care.
- ☐ Make a personal file for your child. It should include:
  - a summary of important information about your child like date of birth, name and address of your child's doctor, dates of entry into school, dates of evaluations.
  - names, titles, and phone numbers of those providers involved in any way. List dates of contacts.
- ☐ Keep notes of conversations or conferences about your child. Keep a record of questions asked and answers given.
- ☐ Ask for written copies of test results, letters, evaluations, comments, or discussion on your child. These are your legal rights. All of these must be written in language you can understand. They must be free of jargon and technical language*. You can insist on this.
- ☐ Keep a looseleaf notebook with all this information. Place this handbook with the notebook. Keep the notebook near the telephone.

*For a free copy of "Jargon and Acronyms," a booklet to help you understand the jargon specialists use, write DD Council, State House Station #139, Augusta, ME 04333.

5. Through the Maze of Services

As you read this handbook, your child will probably be in one of three stages along the way to getting help.

1. *Birth*—When physical problems are already present: open spine, cleft palate, arm or leg malformations, or other problems such as Down Syndrome.

2. *The first 2-3 years*—Sometimes developmental delays show up very slowly when a child doesn't keep pace with the expected activities of a certain age; fails to follow movement with eyes; doesn't roll over; seems to have little need for personal contact with others; does not respond to sound or speech.

3. *Children nearing or at school age*—Many small or large signs may signal a problem to parents or teachers: when a child has difficulty with other children; doesn't follow directions; can't pay attention; cannot tell the difference between certain shapes and sounds.

If your family is at the first or second stage, getting started is usually easier. A physical problem may need immediate solution. A parent of a child with spina bifida has said that in the case of some birth defects the first difficult question may be to *treat* or *not treat*. She adds that in nearly every case now there is hope for the child's life. She suggests that new parents ask the hospital staff to put them in touch with other parents of children with disabilities. Those parents can help think through the earliest questions.

Stage three is usually the hardest point to enter a service system of places, people, and assumptions including schools, teachers, I.Q. tests, medical services. Often these people and their services are far apart in their ability to assess the child's needs and prepare a program for him. Sometimes parents are unsure and doubt their own concerns.

The Maine Parent Federation, a statewide coalition of parent groups representing disabilities of all kinds, sponsors the Special-needs Parent Information Network (SPIN). The Network coordinates and delivers training to families of children with special needs to help them participate fully in planning for their children. You may want to call SPIN for more information and parent contacts in your area. SPIN's toll-free number is listed on page 18.

There are some basic steps to expect and plan. They will not be the same for every family. But they will usually include medical care, education and training programs, and support for the family. You may feel more comfortable if you understand the steps that may help you in living with your child. Some of them are listed below.

If your child is very young:

- Get necessary medical care for your child.
- Learn all you can about disabilities. Learn how to care for them.
- Make appointments with a clinic or private doctor or public health nurse to find out more about your child's problems. Ask your doctor to help.
- Decide if you will enroll your child in local programs for preschool or infant development even before you know much about the disability.
- Begin asking questions; find parents of other children with problems like yours.
- Try to start setting your limits so that you will not be so tired or overwhelmed.

If your child is older and you have slowly become aware of a problem or suspected problem, your needs may be a little different from the parent who knows from birth. However, you may have to follow some of the same early steps and these additional steps:

- Use the developmental guide inside the front and back covers of this handbook.
- Get a screening and/or evaluation for your child. Contact your local public health nurse, child development worker from the Bureau of Children with Special Needs, family physician or local preschool project (See pages 48 and 49).
- Ask that principals as well as teachers be present at planning meetings. Decide if your child should be there.
- Keep in touch and follow up as the program goes on.
- Seek out an advocate or contact person on whom you can rely.

The array of services and programs for children with disabilities is very large. You may find that you want a broad overview of the services and support you will need over the coming years. On the next two pages is a chart showing some of these services and where they may fit into the life of your child and your family. Many of them will be repeated at different stages and places; many will be used continuously. The chart may help you see them over a long period of time and give you a sense of how to get through the maze of services.

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A SYSTEM OF SERVICES AND SUPPORT

This chart gives an overview of services and support needed through several stages of a child's life. Most of them are services provided by agencies and organizations. You will find more information about these on the following pages.

TYPE OF SERVICES	INFANT (0-3)	EARLY CHILDHOOD (3-5)
	Infant stimulation Early intervention Programs from voluntary associations, or health centers	Pre-School Public Private centers with comprehensive early training programs Day care Early screening for school placement
	Your doctor Your health department Well baby clinic Early medical treatment First diagnosis/evaluation Genetic counseling	Comprehensive diagnosis/evaluation Clinic or private doctors Continued treatment
	Extended family and friends Parents of other children with disabilities Respite care Babysitters Day Care	Continued family/friend support Respite care Family counseling
	Parent organizations Financial aid	Continued parent organization support Continued financial aid Day care Foster care Adoption services

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Some of this support is more personal. It has been discussed earlier in this handbook. Both kinds of service and support are important to your child. They often work together and are necessary at the same time. As you will see, most extend over a lifetime.

CHILDHOOD (5-12)	FUTURE–TEEN/ADULT
Placement in regular programs Placement in special programs Development of Individualized Education Program–IEP Special education division of local education department Private schools–day residential	Continued screening and evaluation–local education agency Placement in regular or special public school programs Vocational training Activity centers Training centers Workshops for job skills life skills
Follow-up evaluation Continued health care including mental health service	Continued health care, evaluation and treatment
Continued family/friend support Respite care Counseling Residential facilities Private Public Community based, away from home	Continued family support services Future placement arrangements Independent living Group homes Community residential alternatives Residential facilities
Continued parent organizations Continued financial aid Recreation Church Clubs Transportation Advocacy system Legal rights	Parent/voluntary groups Financial aid Continued community services Advocacy system Legal aid Planning wills/trusts

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6. Getting Help

WHAT YOU NEED TO KNOW

Finding the information you need to know is often a difficult and time consuming task. This process can be made easier if you call the regional offices of the Bureau of Children with Special Needs or Mental Retardation. Within these offices are resource developers, as well as other personnel, who can help you locate appropriate services for your child. If you have sought services, then followup will be provided to you to assure that you have received services and that they are meeting your needs.

Your local 0-5 coordination site can provide information and refer you to services in your area. If your child is older, you may also contact the director of special education in your school district. The Special-needs Parent Information Network can put you in touch with other parents and information sources in your area.

YOU AND YOUR DOCTOR

Sometimes the doctor who delivered your baby, your clinic doctor, your family doctor, or your pediatrician may determine that your child is not developing properly. The doctor may have an idea of what the problem is and suggest that your child be examined further. He may give you the names of other specialists. Some of the specialists who could be used are described in the next part of this section. Your doctor may wish to set up the appointment for you. The choice of doctors, however, is yours. You may choose to accept his advice, or you might also seek a second opinion from another specialist. These referrals will take time, and fees will be charged.

FINDING OUT ABOUT YOUR CHILD'S PROBLEM: DIAGNOSIS AND EVALUATION

The first step in the process of getting help is to find out what the problem is—a diagnosis. Perhaps there is not a final answer to the question of what is wrong, but you need to be able to describe your child's problem. Specialists from different fields—health, social services, education and mental health among others—will assess and evaluate your child. Using diagnostic scales, they will make their diagnosis regarding your child's specific area of difficulty. Then they will talk with you about their recommendations and your child's needs.

There are several ways you can get a diagnosis and evaluation of your child. Many people begin with their own doctor, or even in the hospital where the child was born. Some work through the local health department. Here are some examples:

- Your child can be seen by your own doctor.
- Your child can be evaluated by a particular medical specialist recommended by your family doctor.
- Your child can be evaluated by several medical specialists in a comprehensive service.
- Your child can be seen in a child development clinic.

YOU AND THE BUREAU OF HEALTH

A variety of health services is available to you through the Bureau of Health, Maine Department of Human Services. A good place to begin is with local, regional and state public health nursing offices in Maine. The State Public Health Nursing office is listed under the Department of Human Services in your telephone directory.

Other public health nursing services are available through town and city welfare offices as well as through private, non-profit community based agencies. Most community based, home health agencies are listed in the Yellow Pages under "Nurses."

Referral to one of these offices may be done by your physician or you may do it yourself. After you contact the community or Public Health Nursing office, you may receive a home visit by a public health nurse if your questions were not answered during your phone call. During her visit with you, the public health nurse will discuss your child's problem. Her goal is to provide you with information regarding your child's health, make referrals for needed services and help you obtain those which you feel would be helpful. She will not be providing medical treatment. The public health nurse serves as an educational and referral source for you.

The public health nurse may refer you to some of the following

Public law requires that all local school systems locate and evaluate all children, from birth to school age, who may be suspected of having a learning difficulty, physical, or emotional problem which will affect the child's school program.

prevention-oriented programs provided through the Department of Human Services:

- High Risk Infant Program
- Handicapped Children's Program
- Preschool Clinic
- WIC (Women, Infants and Children)
- Child Development Clinics
- Child Development Programs
- Medical Eye Care Program.

The public health nurse will make referrals to any resource for service that your child may require, including services within the Public Health Nursing Division as well as other divisions within the Bureau of Health, Department of Human Services, or private agencies in the state.

THE DIAGNOSIS AND EVALUATION SYSTEM

In Maine, five clinics called Child Development Clinics provide diagnosis and evaluation (D&E) for children aged 0-5 years. These clinics are funded through the Division of Maternal and Child Health and are located in Bangor, Waterville, Portland, Caribou and Lewiston. The clinics have many specialists who work together as a team, often called the interdisciplinary team, who will evaluate and diagnose your child and develop a plan of care. Oftentimes, it is the public health nurse who assists parents in the follow-up to the team's recommendations and plan.

The team is composed of a pediatrician, speech pathologist, public health nurse, clinical psychologist, social worker, and a hearing specialist. It may also include a physical therapist, occupational therapist and a nutritionist. Your child may also receive such tests (blood, X-ray, etc.) as the pediatrician deems necessary. Knowing the nature and extent of your child's problem will help the interdisciplinary team in making its recommendations in your child's plan of care. If your child needs additional diagnostic studies the clinic will refer you to a specialist in your area.

Referral to the Child Development Clinic occurs through your public health nurse, your pediatrician, or even yourself.

The five diagnosis and evaluation centers funded through the Division of Maternal and Child Health are:

The Child Development Clinic
Maine Medical Center
22 Bramhall Street
Portland, Maine 04102
Contact: Eileen Harris
(207) 871-6186

Infant Development Clinic
Eastern Maine Medical Center
489 State Street
Bangor, Maine 04401
Contact: Paula Thomas
Public Health Nursing
(207) 945-7550

Aroostook County Clinic
Cary Medical Center
Box 37, Van Buren Road
Caribou, Maine 04736
Contact: Denise Scott
(207) 498-3111

Central Maine Child Development Clinic
Central Maine Medical Center
76 High Street
Lewiston, Maine 04240
Contact: Marie Lowell
The Child Health Center
88 Main Street
Norway, Maine 04268
(207) 743-7034

The Children's Development Center
Mid-Maine Medical Center
Seton Unit
Waterville, Maine 04901
(207) 872-4305

If your child has a serious medical problem, a referral may be made to a larger medical facility such as the Pediatric Department of the Maine Medical Center in Portland or the Boston Children's Hospital. It is often frustrating to parents to know that something is wrong with their child and not know what it is. This situation may be discouraging, but provides the next step toward obtaining the most appropriate treatment and/or services for your child.

CHILD FIND

Every school district has a *Child Find* program for early identification and screening of children who may have a disability. Child Find is another resource for parents.

Public law requires that all local school systems locate and evaluate all children, from birth to school age, who may be suspected of having a learning difficulty, physical, or emotional problem which will affect the child's school program. School systems espe-

cially want to find children who need help before they get to kindergarten age. After identifying a possible problem, the school personnel will often try to work with other agencies like health departments in testing and follow-up.

For aid from Child Find, parents should call their local special education director listed in the telephone directory under "schools" or the local 0-5 coordination site listed on pages 48 and 49.

OTHER OPTIONS

In Maine there are many other services for evaluation of specific problems: eye clinics; hearing, language and speech centers; dental care centers.

To locate centers in your area, use the directories listed in the last section of this handbook.

The Bureau of Children with Special Needs can evaluate and diagnose children with autism. The bureau's services also include follow-up treatment, respite care, family training and tutoring services. (See page 46.)

The Maine Head Injury Foundation, an organization for persons with head injuries and their families, fosters support groups throughout the state, distributes information and encourages the Maine legislature and service providers to establish and maintain appropriate rehabilitation services for children and adults with head injuries. (See page 18.)

GETTING TREATMENT FOR YOUR CHILD

Once you and the professionals can describe your child's problem, a plan for care and treatment can be developed. This will include physical, social, and emotional aspects. You should be able to understand and feel comfortable with the plans. If you are not comfortable, *be sure to ask questions.* Keep in mind that you still may not have a final diagnosis and that the situation may change over time. Beginning positive action for your child may be your most important step. Remember also that you make the final choice of the plan you feel most meets your child's need.

Many treatments might be involved with the care of your child. Some of the words used to describe the treatment may be familiar to you. Others may be new. Below are some of the terms which you might hear when discussing treatment for your child.

Audiology—Special training for hearing problems.

General Practice—Traditionally, the services of a "family doctor" refers to the private offices of a doctor trained in general medicine or sometimes internal medicine. Sometimes, this doctor will help the patient or family manage health problems. This doctor will call in specialists as necessary.

Habilitation—A combination of treatment and therapy required to help a child or young person acquire skills necessary to grow up to be as independent as possible.

Internal Medicine—Special training which covers most medical problems except surgery.

Neurology—Special training which studies problems and diseases of the nervous system.

Nutrition—Science dealing with diet and proper foods to eat for health and for special medical conditions.

Obstetrics—Special training in pregnancy and childbirth.

Occupational Therapy—Special therapy to help people with a disability develop skills necessary to their work and everyday life.

Ophthalmology—Special training for problems with eyes. This doctor may operate on the eyes.

Optometry—Special training for testing eyes and writing orders for glasses or contact lenses.

Orthopedics—Special training which focuses on the skeletal system.

Otolaryngology—Special training for problems of ear, nose and throat.

Pediatrics—Special training in the medical problems of children from birth to teenage years.

Pedodontics—Special training in children's dentistry.

Physical Medicine and Rehabilitation—Special training for doctors in the treatment of persons with physical disabilities.

Physical Therapy—Special training to use heat, massage and exercise to improve muscles in the body and improve coordination.

Podiatry—Special training for problems of the feet.

Psychiatry—Special training to treat mental and emotional problems. Doctor can prescribe drugs or medical treatment.

Psychology—Special training for mental and emotional problems. Does not include prescribing drugs or medical treatment.

Rehabilitation—A combination of all kinds of treatment and therapy required to assist a person with disabilities to get or regain skills necessary to be as independent as possible.

Speech Therapy—Special therapy for speech problems or learning problems.

Urology—Special training in problems of the urinary system.

Vocational Rehabilitation—Special therapy to help a person with disabilities select an occupation or career and learn the tasks necessary to perform in a job.

FOLLOW-UP

An agency that is providing treatment for your child should be concerned with how you and your child are doing. It is the agency's responsibility to help you follow through with recommendations and find out whether you are having any problems. Someone from the agency, perhaps a social worker, may contact you. Although this is an important part of treatment, not all agencies follow their patients closely. *If you are having trouble, do not hesitate to contact the agency and ask for additional help.* You may also request a date when you can expect a progress report on your child. This will help you make additional decisions.

NEXT STEPS FOR YOU AND YOUR CHILD

1. ADDITIONAL SERVICES FOR YOUR CHILD

2. SERVICES FOR YOU AND YOUR FAMILY

3. FINANCIAL AID

There are many services and programs in addition to health, medical, and diagnostic services which will be necessary for your child and your family. Some cover major areas of life such as education, vocational training, and health. Others are aimed at helping you to

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better understand and help your whole family with the care of a person with disabilities.

The next part of this section reviews some of the services needed and available. Some for your child are:

- infant programs, including day care, foster care, nursery schools
- public school education
- recreation
- transportation
- religious training
- special equipment

Some for you and other family members are:

- information and training
- genetic counseling
- mental health counseling
- respite care
- support groups

EXTRA HELP FOR YOUR BABY

The earlier you begin the better. The more help you can give your baby during the early years, the more you are improving chances for success in school and later life. Some associations for retarded citizens, cerebral palsy centers, and other agencies now provide infant stimulation and treatment programs. These services are known as early intervention, and may start as young as 4 weeks old.

All babies need to interact with their parents and the people around them. They need to be held, played with and talked to. Babies with special problems may need more stimulation than typical babies. There are special classes where parents can learn exercises and techniques for working with their babies to strengthen their muscles and increase their awareness of the environment. In order to make these programs work effectively, you—the parent—must be actively involved. For information about programs, call the regional Bureau of Children with Special Needs office or 0 to 5 coordination site nearest you.

HEAD START

Head Start is a preschool program for children not enrolled in more traditional, privately funded programs. It is paid for by government funds. The preschool programs are usually run by county community action offices. Every Head Start program has at least ten percent of its enrollment spaces available to children with developmental disabilities. Phone numbers can be found by calling county community action offices and asking for the Head Start coordinator.

VOLUNTARY AGENCIES

Voluntary agencies such as associations for retarded citizens and cerebral palsy centers often operate daytime preschool centers with special treatment services.

Contact the association which may best serve your child's need. Use the lists of groups in Section 2 of this handbook.

As your child grows older, voluntary associations may be helpful in providing group or semi-independent living arrangements, job training, and various types of supported employment. Voluntary agencies who serve adults with disabilities often work with public school teachers and administrators and parents to plan for the transition of young adults from school to living and working in the community.

LICENSED DAY CARE

For some families, day care for all or part of the day may be needed. In nearly every community there are day care centers for young children. Many of these will accept children who have special needs for full or part day care. Most parents will need to talk with day care center directors to determine if a particular center will meet their child's needs. Other sources of day care are private homes where three to twelve young children per day are cared for under a license granted by the state. Some of these day care providers will also take children with disabilities.

In Maine, day care homes may be either licensed or registered by the Department of Human Services. Both day care centers and family homes may be located through the regional or branch offices of the Bureau of Children with Special Needs and those of the Department of Human Services. These offices can assist with the placement of children with disabilities in the appropriate child care setting. This will help make sure that children receive the most useful child care program. It also allows for follow-up between programs and families. Call the Bureau of

Children with Special Needs or Department of Human Services regional office listed on the chart of local government agencies for information on day care.

YOUR CHILD'S EDUCATION

Times have changed. The thinking in the past was that children with disabilities should be separated from other children. Children with disabilities were felt to require special services which could only be provided in special schools. Now the thinking has changed. To the extent possible, educators feel students with disabilities should be placed together with students who do not have disabilities. School experiences should be as normal as possible. While this does not mean that your child will automatically be in the regular classroom, it does mean that your child will receive extra attention and planning to meet his or her individual needs.

The laws state that all children with disabilities, regardless of the type or degree of disability, deserve a free public education. Recent laws now assure your child with special needs, ages 3-21, the right to be educated in the public school system just as are youngsters who not disabled. Both state and federal laws now insure this right. (Maine P.L. Chapter 693, 1982 and Federal Public Laws 94-142 and 99-457.)

There are several special sections of these laws which you will need to understand well. Each of them guarantees services to your child and ways to make sure those services happen. These are outlined in *"Special Education for Parents."* This and other publications of help to parents of children with disabilities are available from the Developmental Disabilities Council, State House Station #139, Augusta, Maine 04333. The Special-needs Parent Information Network (See page 18.) can also supply information and publications to you.

Every child with a disability will have an education program based on his particular skills, problems, and needs. The plan for your child will be in a written form. It is called an Individualized Education Program (IEP). You must be involved in developing, reviewing, and approving this plan. You may see all the records which the school keeps on your child. The Individualized Education Program will include special education and related services as needed, such as:

- physical therapy
- occupational therapy
- speech, hearing therapy
- counseling
- transportation

This plan is a reversal from labeling all children in groups and then deciding on an educational program. Each child's needs must be looked at by a team of specialists. Then the plan is made. And you are an important member of that team.

Perhaps the most important part of this law is that parents are part of the planning group. In most cases you spend the most time with your child and are knowledgeable about significant aspects of

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his life. You can help make decisions, not just accept them.

DUE PROCESS

If you feel that your child's educational placement and/or program is not appropriate, you may request a hearing. At that time, decisions about your child will be reviewed. Such a hearing is part of the "due process" plan also required by law.

If your child does require a special program which cannot be provided in the public schools, the Maine Department of Educational and Cultural Services is required to make arrangements with private sources or go outside the State of Maine.

For additional information, you should contact the director of special education in your local education agency.

For general information about State Department of Educational and Cultural Services policy, your rights as a parent and other educational services, contact the Division of Special Education, Department of Educational and Cultural Services at 289-5954.

VOCATIONAL REHABILITATION

Although your child may be very young, you may already wonder what will happen as he grows older.

Much has changed in our image of the person with a disability as a useless non-productive member of society. The State Department of Human Services has a Bureau of Rehabilitation. This office often gives needed training to help persons with disabilities become persons with skills, jobs, and paychecks—and self-respect. The programs include support of some training programs, emphasis on community based programs, services geared to personal needs, and follow-up as persons move into the working world. Special help is given to people with severe disabilities.

YOUR CHILD AND RECREATION

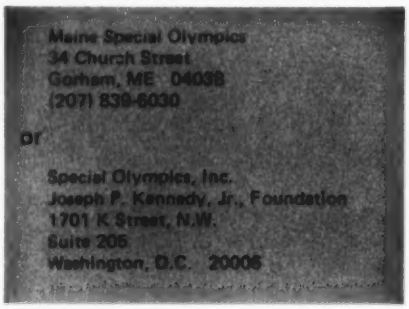
Recreation includes many different activities: physical fitness, socializing, playing, and generally having fun. Your child is entitled to recreational programs and the use of public recreational facilities just as other children are. These programs are supported by your taxes or organizations which are bound by non-discriminatory practices. You may have to insist that your child be included in recreational activities.

SPECIAL PROGRAMS

Some groups have special programs to meet the special needs of childen with disabilities. Others have programs which try to put children with disabilities together. Some youth groups such as 4-H, Scouts, YMCA, and YWCA have made efforts to include children with disabilities. You should contact your local groups and inquire. If none are underway, encourage the group to start one. If you never ask for or demand a service, you may not receive it. Your local recreation department is also a good source of information. Some areas have programs for persons with disabilities aimed at developing physical and social skills. Call your town office, city hall or recreation program to learn more about recreation programs in your area.

SPECIAL OLYMPICS

Some programs are exclusively for individuals with disabilities. The Maine Special Olympics has an annual competition in both winter and spring. People who are mentally retarded as well as physically disabled compete for awards in athletic events such as swimming, bowling, track, field events and gymnastics during the spring. In the winter the events change to those related to snow. For information on Special Olympics contact:



To the extent possible, educators feel students with disabilities should be together with students who do not happen to have disabilities. School experiences should be as normal as possible.

SUMMER CAMP AND TRAVEL

Summer camp programs, both day and overnight, geared to children with disabilities, give them a chance to explore a new environment and give parents a chance to have a vacation as well.

Playing and being with friends is an important part of being a child. You may recall some of the adventures you had as a child. The extra effort it requires will give your child a chance to have similar happy recollections. Many associations for retarded citizens provide day camp programs. Residential camps for children and adults with disabilities are also available. For more information contact your local association for retarded citizens, cerebral palsy center, or the Pine Tree Society for Handicapped Children and Adults.

YOUR CHILD'S TRANSPORTATION

Transportation is a problem frequently mentioned by parents and individuals who are disabled. People can take advantage of the services which are available only if they can get to them. While much progress has been made in making public transportation accessible to citizens with disabilities, there is still a long way to go to reach this goal.

Both public and private organizations provide transportation to schools, work, recreational and medical facilities. Sometimes, agencies arrange for buses or car pools using specially designed vans. If a child can use public transportation, the car fare may be provided by the agency.

All public school systems must give free transportation to and from school to children with disabilities which limit free physical movement. Some areas have special transportation services. For information about these services, call the community action program in your community, local 0 to 5 coordination site or the nearest regional Bureau of Children with Special Needs office.

YOUR CHILD AND YOUR CHURCH

Many parents suffer a kind of religious crisis when they are confronted with the reality of a child with disabilities. Some turn away from their church, but others reaffirm or re-establish their commitment to a religious group. Many are seeking extra support during this crisis. Your rabbi, priest, or minister may not be familiar with members of the congregation who are disabled. Hopefully though, he or she will be willing to become more informed and wish to consult chaplains in major hospitals to better understand some of these problems.

Both children and older persons with disabilities should have opportunities for religious education and participation in religious services. People with disabilities have the same values, feelings, and spiritual needs as anyone else. The chance for development, as desired, of the "inner" life is important to total human growth.

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Do not be afraid to contact your church about involving people with disabilities in the services. It often becomes as valuable an experience for the church as for a person with disabilities.

YOUR CHILD'S SEXUALITY

As your child grows and develops, you may wonder how to deal with his or her sexuality. The area of sexuality is a difficult one for many parents and children. When the child is mentally or physically disabled, dealing with sexual feelings and behavior may be even more difficult. There is much more openness today and more exploring of answers to these questions. Sometimes conflict may develop between the rights and needs of the parents and the rights and needs of the child. Your child or adolescent who is disabled has a need to express sexual feelings, in both physical and emotional ways. Sexuality is a part of all human development and should be considered as a normal aspect of growth.

You as the parent may be afraid of your child's sexual activity. You may want to protect him or her from being harmed or being judged by the community. You may be fearful of pregnancy. You may feel your child is unable to manage relationships with the opposite sex, let alone marriage and possible child bearing. You may not want your child to take any risks in exploring his or her sexual feelings. Children with some physical disabilities may have fears or concerns about their bodies and their sexuality. These are real problems, and there are no easy answers.

There are organizations which have workshop and discussion sessions about sexuality, sterilization, rights and privacy, instruction for persons with disabilities about sex, child bearing, and parenting. You will find help in working on these questions through your local association for retarded citizens, cerebral palsy centers or regional Bureau of Children with Special Needs office.

NEXT STEPS FOR YOU AND YOUR FAMILY

HAVING ANOTHER CHILD

If you are thinking about having other children, you may also

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wonder what your chances are of having another child with a disability. Your family doctor may be able to help you with this. Or, most probably you will want to go to a special center for genetic counseling. A genetic clinic examines the genes in the body's cells. Often a disorder is passed from parent to child by a certain gene or can be found in misformed cells. A genetic study can help parents decide the risk a couple may take when having another child. However, only parents themselves can decide whether or not to have another baby.

Some facilities provide this kind of service. You may want to call one of the following or consult your public health nurse.

Eastern Maine Medical Center
Genetic Laboratory
489 State Street
Bangor, ME 04401
(207) 945-7354 or 1-800-372-8777

or

Foundation for Blood Research
Route 1
Scarborough, ME 04074
(207) 883-4362

WHEN YOU NEED SOME RELIEF FROM TAKING CARE OF YOUR CHILD

RESPITE CARE

All parents need and deserve a break from the constant demand of raising young children. Parenting is hard work. It is good for parents to be able to enjoy each other away from the constant pressures of family. Respite means "rest" or "time out." Having the chance to be away from each other is good for both parent and child. It can help make a child more independent. Sometimes parents are fearful of leaving their child, but having a good place and helpful persons to care for the child is reassuring.

One mother has made this comment:

Allow for alternate patterns of child care—father and child; mother off by self or with other children; child with relative, sitter, or respite care provider. Everyone in the family, from time to time, will need time alone or away from the handicapped child. This will make for a happier family for everyone.

There will be occasions when you are unable to care for your child and will need someone to temporarily take over. This may be due to an emergency, illness, or unexpected trip out of town. Respite care may enable the family to take a planned vacation. These services now exist in many areas to help meet this need.

Call the Maine Respite Project, 1-800-227-7706, for additional information.

ALTERNATIVE LIVING ARRANGEMENTS

Keeping a baby in a home-like environment during the early years is extremely important. This time is a critical period in your child's development, and you and your family can provide the best care. Agencies in the community are providing services to help you keep your child at home. Their services were described earlier and include: child care, respite care, infant stimulation, and school programs.

Sometimes parents cannot manage at home and may need other alternatives. A parent might consider placing a child in foster care or in an adoptive home. Funds are available to families who are willing to care for children with disabilities.

Foster placement continues to provide a home-like environment. Contact your regional Bureau of Children with Special Needs office or regional Human Services office.

There are two types of community based residential programs: group homes and pediatric intermediate care facilities, which are becoming more available for children who are physically or mentally disabled. Group home living arrangements allow for children to live with others their own age, maintain a normal daily routine, and receive the supervision which they require. Many children show considerable growth in the skills necessary for increased independence, which promotes a sense of self-esteem. Your child may be eligible for such a program. In an intermediate care facility there is specialized care available for the child with special needs. Voluntary agencies may be able to provide assistance in finding a group home.

Often parents say it is hard to separate from their child and will

need help in doing this. It is necessary to recognize that children need to learn skills which allow them to live as independently as possible. You will want to continue your involvement in your child's growth and progress. It is best to have your child or young adult move into a foster home, group home or other living arrangement while you are able to check on the living situation and personal adjustment.

For information about private residential services contact the regional office of the Bureau of Children with Special Needs.

If a residential placement is determined to be best for you and for your child, you will want to consider several factors in making a selection. You will want to know what services are offered, what kind of plan will be developed for your child's care, and the number of staff available to care for the residents. You will want to make sure that your child receives proper treatment once he or she has been admitted to a facility. You will want to be involved with your child's program and monitor it to your own satisfaction. Parent groups may be able to assist you in making these decisions concerning the selection of a facility and your involvement in your child's life there.

COUNSELING FOR SPECIAL PROBLEMS

Sometimes you may feel as though you cannot cope with the situation. You may feel especially

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troubled by some of your child's behaviors. You may be upset by the rest of the family's reaction to your child with a disability, or perhaps brothers and sisters of the child are having difficulty adjusting. Any of these problems may require special counseling.

There are many places where you can go to get that counseling. Parent groups are a good place to turn. Many such groups hold training sessions, workshops, or parent sharing groups. Even "friend-to-friend" consulting may help. In many communities there are courses offered in parenting skills. These skills are needed by parents of all children. For most parents, these are skills that must be learned. Many parents find these classes helpful. Additionally, a mental health center in your area may be a resource to you. A list of these centers is included in the Appendix.

Always keep in mind that the frustration you are experiencing, others have also felt before you. You are not alone; many families have needed and accepted counseling help.

CHILD ABUSE

Sometimes a parent of a child with a disability or a child who is not disabled may begin to resent the constant demands made of them. Parents are under a great deal of pressure. A parent might feel so angry and resentful that he or she feels like hurting the child and actually does. Parents who have experienced similar feelings have come together, anonymously, to discuss their frustrations. This kind of group is often an outlet for parents under this overwhelming pressure. For more information contact:

Parents Anonymous
Bangor 941-2911 Caribou 498-2578
Portland 871-7443 Waterville 873-1148

Other sources for help in situations that may lead to real injury or harm can be found at the regional Bureau of Children with Special Needs offices. It is good to keep a list of hotline numbers to call for emergencies of any kind.

FUTURE PLANNING: WILLS, TRUSTS, AND GUARDIANSHIP

It may seem early in your child's life to be concerned about the future care of your child. Yet nearly every parent feels troubled and concerned about plans for care, protection, and advocacy for their child should anything happen to the parent. This "anything" usually means death of the parent or the inability to continue care of the child due to sickness or disability.

It is well to remember that many people with disabilities will be able to care for themselves and make their own decisions. These people will probably not need guardianship. Many others will need only a little help. Some will need continued care and supervision. These individuals will most likely need guardianship. Yet each person with disabilities has rights and abilities and these must be given first priority in all decisions in questions of guardianship.

Wills, trusts and guardianship are means of providing financial help as well as personal protection in the future. Most families, no matter how small their income, want to have a will for all of their children's benefit. Future planning raises many questions: What is the right time to name a guardian? How can I be sure my child needs a guardian? Who shall I name as guardian? How can I be sure my child has financial protection? What about other children in the family?

Answering questions like this is difficult and often emotional. Most parents cannot do this alone and should use the advice of an attorney. You may contact the Bureau of Children with Special Needs regional office in your community or the Bureau's Central Office in Augusta for information on guardianship, 289-4200.

FINANCIAL HELP

Families caring for a child with a disability will most often have additional financial burdens. There may be special medical treatment, braces, hearing aids, glasses, tutors, special clothing, wheelchairs, learning materials, classes, and homemaking help. The list will seem very long to the parent just beginning. Not many families can pay for everything from their own incomes. There are many ways for families of children with disabilities to get help in paying these costs.

Finding out where financial help is available and the process of getting it will take time and may become frustrating. However, if your family meets the requirements for financial help, you should not feel guilty about claiming it. Financial help may relieve some of your worries.

Working parents with moderate income may contact the Division of Maternal and Child Health for information on income eligibility requirements. Families with lower income may want to contact some of the following resources.

SOCIAL SECURITY

The largest government support program is Social Security. More than likely someone in your family has paid into the Social Security fund. Most people who work for any length of time have had Social Security deducted from their check. Social Security is not welfare. A special part of the Social Security program is set aside for families with a member with a disability.

Monthly Social Security benefits are available to:

- Workers who become severely disabled before the age of 65
- Retired workers over 62 years of age and their dependents
- Children of retired, disabled, and deceased workers, provided that the children are either under 18 years of age, or were severely disabled before the age of 22 and continue to be disabled.

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SUPPLEMENTAL SECURITY INCOME (SSI) FOR AGED, BLIND, AND DISABLED

Another Social Security program is called Supplemental Security Income (SSI) for Aged, Blind, and Disabled. Some people do not have money to pay for their basic needs, such as food, rent, and clothes. If they are 65 years of age or older, or they are of any age, including children, and are blind or disabled, they may receive payments from the Social Security Administration. These payments come each month.

A parent, guardian, or other responsible person can apply for a child or adult with disabilities to receive payments. The Social Security office then decides if a person comes under the rules for payment.

For information and application forms for Social Security programs, call your local Social Security office. If you find the process difficult, your public health nurse, 0 to 5 coordination site or social worker may be able to provide assistance. Local telephone numbers for Social Security are listed in the telephone book under Social Security Administration.

VETERANS ADMINISTRATION

The Veterans Administration is another government agency which might provide some assistance. CHAMPVA, the Civilian Health and Medical Program of the Veterans Administration, is a health and medical care plan. Financial aid for medical care is provided to a spouse or child of a veteran (living or deceased) who has a 100% total disability (i.e., determined to be permanently unemployable). The disability must be the result of a service-related injury from the time the person was in military service. Normally, benefits end when the dependent child turns 18 years of age. However, if the child is not able to support him/herself because of mental or physical disabilities that existed before the age of 18, the child can continue to receive benefits. For information about this program, call:

VETERANS BENEFITS FOR FAMILIES

A second program from the Veterans Administration provides for the education of wives, widows, or children of veterans who are 100% permanently disabled. Again, the disability must have come from an injury during the time a person was in the service. The spouse and children must be between 18 and 26 years of age to receive educational help. Special attention is given to the selection of training programs for children with disabilities. Contact:

MEDICAID

At the state level there are several kinds of financial aid to which you may be entitled. Medicaid, or the Maine Medical Assistance Program, helps people of all ages who cannot afford to pay for necessary medical and health care services.

Anyone who receives AFDC, is a foster child, or receives Supplemental Security Income (SSI, explained above) may be issued a Medicaid card. A family may get Medicaid if it earns a minimum monthly income, or none at all, and owns little or no property. A family may have a higher income and not receive AFDC or SSI, but have very high medical bills, often because of a child with disabilities. That family might be eligible for a Medicaid card if they meet some other financial requirements.

Most private doctors accept Medicaid. The program also allows your child to receive hospital care, nursing home care, laboratory services, dental care and many other related services. Some services within the areas of care may not be covered. Each family can select the hospital within Maine where it would like to receive care. To find out if you are eligible, call the regional Human Services office nearest you.

MEDICARE

Adult children with disabilities who receive Social Security benefits from their parents' employment can receive Medicare benefits. Any child under age 18, disabled or not, may receive Children's Benefits if the parent is retired, disabled, or deceased. When the child reaches age 18, his

status changes. If he is disabled, he becomes a disabled adult child and continues to receive benefits. After two years, he will be eligible for Medicare benefits. This is part of the law giving Medicare coverage to anyone who has received disability cash benefits for a period of two years.

In some instances it might be better to receive Medicare than Medicaid. Those persons who cannot get Medicaid because of the amount of their income, could be eligible for Medicare if they are receiving Social Security disability cash benefits. An individual who receives both SSI and Social Security might be eligible for both types of medical assistance.

ADOPTION

For families who are considering adoption, special funds are available to help care for children with special needs. For more information on this program call:

The Adoption Unit
Department of Human Services
Regional Offices

OTHER PROGRAMS

There are a number of other income support programs. Most are based on income level and sometimes other requirements. Programs include:

- Aid to Families with Dependent Children (AFDC)
- Food Stamps
- Nutrition Program for Women, Infants and Children (WIC)
- Rehabilitation Services
- Emergency Assistance Grants
- Private Voluntary Agencies

You may be eligible. Call the Department of Human Services regional office or 0 to 5 coordination site near you. Ask the person who answers to explain who qualifies for each program.

INSURANCE BENEFITS

There is another kind of assistance which does not involve direct payments of money. You may have your own medical insurance policy. Perhaps you are not quite certain what benefits are covered, or you feel as though something has not been properly handled. You can request that a person in the Bureau of Insurance office review your policy and explain any questions to you. This service is free of charge. For additional information call:

Consumer Services Division
Bureau of Insurance
289-3101/Toll Free 1-800-452-8479

TAX DEDUCTIONS AND TAX CREDITS

Included in financial support should be a sizeable list of income tax deductions and credits. Every parent should use these benefits. For a list of deductions and tax credits, contact the Internal Revenue Service office nearest you.

Local telephone numbers for Internal Revenue Service are listed in telephone books under Internal Revenue Service.

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Insights

Much of what you have read in this handbook is based on the experience of parents who have children who have disabilities. As you look back through the handbook, and as you look forward in planning for your own child's future, here are some thoughts from those parents:

He is lucky, this little boy of mine. He will not conquer the worlds of the academic, the scientific, or the great doers. But he has a unique appreciation for those ordinary rites of life that seem only dull or jaded to the rest of us.

My son will be without most of the normal frustrations, anxieties, and decisions (choices), but he will have some accomplishments, some human dignity, and some sense of personal worth. He has the use and enjoyment of all his faculties, even with limited understanding of the complex world around him.

Things are different now. There are good programs for infants, preschoolers, school-aged children, and if there aren't, parents are no longer powerless to get their children what they need. Parent associations are at hand to see to it that programs are provided, as well as to offer the softer comforts of companionship and understanding of other parents "in the same boat." And there are warm, emphathetic professionals working with children and families. These are good days—a good start towards what we want for our children—the best. (Milligan and Trainer)

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Appendix

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DIRECTORY OF LOCAL AND REGIONAL GOVERNMENTAL OFFICES

DEPARTMENT OF HUMAN SERVICES

Services available through most regional offices include:

- AFDC
- Food Stamps
- Medical Assistance
- Boarding and Nursing Home Assistance
- Public Health Nursing
- Support, Enforcement and Location Services
- Licensing & Certification
- Welfare Employment, Education & Training
- Protective Services: adults and children
- Substitute Care: adults and children
- Court Study Services
- Family Day Care
- Family Crisis
- Adoption Services
- Foster Home Program: adults and children
- Children's Emergency Services
- Children's Emergency after hours:
  - Toll Free 1-800-452-1999
- Problem Pregnancy Services
- Social Services

REGION I

Cumberland and York Counties

- PORTLAND:
  - Tel: 774-4581
  - Toll Free: 1-800-482-7520
- BIDDEFORD
  - Tel: 282-6191
  - Toll Free: 1-800-322-1919
- SANFORD:
  - Tel: 324-9472
  - Toll Free: 1-800-482-0790

REGION II

Androscoggin, Franklin and Oxford Counties

- LEWISTON
  - Tel: 795-4300
  - Toll Free: 1-800-482-7517
- FARMINGTON
  - Tel: 778-6054
  - Toll Free: 1-800-442-6382
- MEXICO
  - Tel: 364-7884
  - Toll Free: 1-800-482-0702
- SOUTH PARIS
  - Tel: 743-7716

REGION III

Kennebec, Knox, Lincoln, Sagadahoc, Somerset and Waldo Counties

- AUGUSTA
  - Tel: 289-2851
  - Toll Free: 1-800-452-1926
- ROCKLAND
  - Tel: 594-2521
  - Toll Free: 1-800-432-1680
- SKOWHEGAN
  - Tel: 474-5551
  - Toll Free: 1-800-452-4602
- BATH *(Food Stamps & AFDC only)*
  - Tel: 443-3765

REGION IV

Hancock, Penobscot, Piscataquis and Washington Counties

- BANGOR
  - Tel: 947-0511
  - Toll Free: 1-800-432-7825
- CALAIS
  - Tel: 454-2131
  - Toll Free: 1-800-622-1400
- DOVER-FOXCROFT *(Food Stamps and Public Health Nursing only)*
  - Tel: 564-3444
  - Toll Free: 1-800-432-1641
- ELLSWORTH:
  - Tel: 667-5361
  - Toll Free: 1-800-432-7823
- MACHAIS
  - Tel: 255-8641
  - Toll Free: 1-800-432-7846

REGION V

Aroostook County

- CARIBOU
  - Tel: 498-8151
  - Toll Free: 1-800-432-7366
- FORT KENT
  - Tel: 834-3934
  - Toll Free: 1-800-432-7340
- HOULTON
  - Tel: 532-9531
  - Toll Free: 1-800-432-7338
- PRESQUE ISLE
  - Tel: 498-8151

COMMUNITY MENTAL HEALTH CENTERS

Aroostook Mental Health Center (Caribou)	498-6431
Community Health and Counseling Services (Bangor)	947-0366
Kennebec Valley Mental Health Center (Waterville)	873-2136
Tri-County Mental Health Services (Lewiston)	783-9141
Maine Medical Mental Health Center (Portland)	871-0111
York County Counseling Services, Inc. (Saco)	282-7504
Bath-Brunswick Mental Health Association, Inc. (Brunswick)	729-4171
Mid-Coast Mental Health Center (Rockland)	594-2544

DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION

BUREAU OF MENTAL RETARDATION (BMR)

BUREAU OF CHILDREN WITH SPECIAL NEEDS (BCSN)

REGION I

Aroostook County
BMR and BCSN; Tel: 764-2010

REGION II

Hancock, Penobscot, Piscataquis and Washington Counties
BMR; Tel: 941-4360
BCSN; Tel: 941-4400

REGION III

Kennebec and Somerset Counties
BMR; Tel: 289-2205
BCSN; Tel: 289-7130

REGION IV

Androscoggin, Franklin and Oxford Counties
BMR and BCSN; Tel: 795-4500

REGION V

Cumberland and York Counties
BMR; Tel: 879-4270
BCSN; Tel: 879-4126

REGION VI

Knox, Lincoln, Waldo and Sagadahoc Counties
BMR and BCSN; Tel: 354-8766

DIRECTORIES OF SERVICES

MAINE DEPARTMENT OF HUMAN SERVICES DIRECTORY OF SERVICES

A directory which lists the services available from the various Bureaus and Divisions within the Department of Human Services and the locations at which services are provided. Copies may be obtained at no cost from:

Office of Public Affairs
Department of Human Services
State House Station 11
Augusta, ME 04333
Tel: 289-3707

PROGRAMS SERVING MENTALLY RETARDED PERSONS IN MAINE

A directory published by the Bureau of Mental Retardation which contains, by their regions, listings of services for children and adults. This directory may be obtained from:

Bureau of Mental Retardation
State House Station 40
Augusta, ME 04333
Tel: 289-4200

SPECIAL EDUCATION DEFINITIONS (P.L. 1982 Chapter 693, § 7001)

§ 7001. DEFINITIONS

As used in this subpart, unless the context otherwise indicates, the following terms have the following meanings.

1. **Agency.** "Agency" means an agency, school, organization, facility or institution.

2. **Exceptional student.** "Exceptional student" is an individual who:

A. Has reached 5 years of age on or before October 15th;

B. Has not reached 20 years of age at the start of the school year; and

C. Requires special education because of an impairment in one or more of the following:

(1) Vision;
(2) Hearing;
(3) Speech and language;
(4) Cerebral or perceptual functions;
(5) Physical mobility functions;
(6) Behavior; or
(7) Mental development or maturation.

3. **Mentally retarded.** "Mentally retarded" means handicapped in mental development or maturation.

4. **Preschool handicapped child.** "Preschool handicapped child" means a person who:

A. Has reached 3 years of age;

B. Has not reached 5 years of age on or before October 15th;

C. Requires special services because of impairment in one or more of the following:

(1) Vision;
(2) Hearing;
(3) Speech and language;
(4) Cerebral or perceptual functions;
(5) Physical mobility functions;
(6) Behavior; or
(7) Mental development or maturation.

5. **Special education.** "Special education" means classroom, home, hospital, institutional or other instruction; educational diagnosis and evaluation; transportation and other supportive assistance; services, activities or programs, as defined by the commissioner, required by exceptional students.

6. **Special education facility.** "Special education facility" means a public or private school, or portion thereof, intended for use in meeting the educational and related needs of exceptional students.

7. **State licensed agency.** "State licensed agency" means an institution or facility licensed by the State to provide education, emotional or mental health services, alcohol or drug rehabilitation, boarding care or other child care services to a person between the ages of 5 and 20 years.

GLOSSARY OF ACRONYMS

Commonly used Acronyms
(State and Federal)

AFDC	Aid to Families with Dependent Children
BCSN	Bureau of Children with Special Needs
BMR	Bureau of Mental Retardation
CDS	Child Development Services
CP	Cerebral Palsy
DDC	Developmental Disabilities Council
D&E	Diagnosis and Evaluation
DECS	Department of Educational and Cultural Services
DHS	Department of Human Services
DMH/MR	Department of Mental Health and Mental Retardation
EPSDT	Early and Periodic Screening Diagnosis and Treatment
ICF/MR	Intermediate Care Facilities for the Mentally Retarded
IEP	Individual Education Plan
IPP	Individual Prescriptive Program
P&A	Protection and Advocacy
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TTY	Teletypewriter
VA	Veterans Administration
VR	Vocational Rehabilitation

For a more complete list of acronymns contact the DD Council, Station #139 Augusta, Maine 04333, and ask for "*Jargon and Acronymns,*" a booklet for parents, educators, media persons, students and social workers.

REFERENCES

Maryland State Planning Council on Developmental Disabilities, *Looking Forward,* A Guide for Parents of Children with Disabilities, 1980.

ADDITIONAL READING

Moore, Cora Lee; and Morton, Kathryn Graham, *A Readers Guide for Parents of Children with Mental, Physical or Emotional Disabilities.* Washington: USDHEW, DHEW Publication No. (HSA) 77-5290, 1976.

A Handicapped Child in the Family, Readings for Parents. Available from:
Washington County Children's Program
P.O. Box 311
Machias, ME 04654

DIRECTORY OF CHILD DEVELOPMENT SERVICES OFFICES

These 16 sites provide coordination of services for children with special needs and refer children and their families to services.

Some of these offices may be moving into more accessible locations. Should you need assistance in contacting your local office, call the SPIN office at 1-800-325-0220.

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CDS--A.P.P.L.E.--Aroostook County
One Vaughn Place, Suite 340
Caribou, ME 04736
Tel: 493-6687 or 498-3749

CDS--CO-STEP
237 Oxford Street
Portland, ME 04103
Tel: 874-8082

CDS--The First Step
618 Main Street
Lewiston, ME 04240
Tel: 795-4022

CDS--Franklin County
Mt. Blue Health Center
RR #4, Box 5122A
Farmington, ME 04938
Tel: 778-6262

CDS--The GUIDE Program
P.O. Box 312, (Mayo Street School Annex)
Dover-Foxcroft, ME 04426
Tel: 564-3115

CDS--Hancock County
78 Union Street
Ellsworth, ME 04605
Tel: 667-7108

CDS--Lincoln County Preschool Project
PO Box 1114
Damariscotta, ME 04543
Tel: 563-1411

CDS--Mid-Coast Children's Services
11 Maple Street
Rockland, ME 04841
Tel: 594-8474

CDS--Opportunities for
Preschool Children
P.O. Box 272 Main Street
Norway, ME 04268
Tel: 743-9701

CDS--Project PEDS
MMMC-Seton Unit
Chase Avenue
Waterville, ME 04901
Tel: 872-4220

CDS--Penobscot County
376 Harlow Street
Bangor, ME 04401
Tel: 947-8493

CDS--SEARCH
5 Paul Street
Brunswick, ME 04011
725-6365

CDS--Washington County
P.O. Box 311 12 Free Street
Machias, ME 04654
Tel: 255-8466

CDS--So. Kennebec Preschool Program
RR #5, Box 1920
Augusta, ME 04330
Tel: 623-4989

CDS--Waldo County Preschool Services
P.O. Box 294 66 Anderson St.
Belfast, ME 04915
Tel: 338-1177

CDS--York County
10 Storer Street
Kennebunk, ME 04043
Tel: 985-7861

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The Very Special Arts Festival
page: 36

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WHAT IS THE DEVELOPMENTAL DISABILITIES COUNCIL?

We, the Developmental Disabilities Council, a federally mandated body, consist of people with developmental disabilities, family members, and state and private providers. We have one mission, one purpose: to create a common vision and an atmosphere for social change to empower people with developmental disabilities to achieve their highest level of self-determination so that all people are recognized for their self-worth, their abilities, and their contribution to the community, and can fulfill their individual potential as full and active citizens. This will be accomplished by harnessing the resources and energies of all people, and then by identifying needs and developing a comprehensive plan that recognizes the present while looking to the future.

We will advocate for and with persons who can effectuate the required changes, whatever they may be.

- Our vision is clear.
- Our mission is difficult.
- Our resolve is not diminished.

The dignity of people with developmental disabilities and their families must be recognized.

You may write us at:

Maine Developmental Disabilities Council
State House Station #139
Augusta, Maine 04333

Our telephone number is (207) 289-4213. For people with disabilities and their family members, our toll-free telephone number is 1-800-244-3990.

NON-DISCRIMINATION NOTICE

In accordance with Title VI of the Civil Rights Act of 1964 (42 U.S.C. §2000d **et seq.**) and 45 C.F.R. Part 80, Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. §794) and 45 C.F.R. Part 84, the Age Discrimination Act of 1975, as amended (42 U.S.C. §6101 **et seq.**) and 45 C.F.R. Part 91, the Maine Human Rights Act (5 MRSA §4551 **et seq.**), and Title IX of the Education Amendments of 1972, the Maine Department of Mental Health and Mental Retardation does not discriminate on the basis of sex, race, color, national origin, handicap or age in admission or access to or treatment or employment in its programs or activities. Our Department's Affirmative Action Officer coordinates our efforts to comply with the U.S. Department of Health and Human Services regulations and the U.S. Department of Education implementing these federal laws. Inquiries concerning the application of these regulations and our grievance procedures for resolution of complaints alleging discrimination may be referred to our Affirmative Action Officer, State House Station #40, Augusta, Maine 04333, telephone number: (207) 289-4289 (Voice) or (207) 289-2000 (TDD), or to the Assistant Secretary of the Office of Civil Rights, Washington, D.C.

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months	A. Does he support himself on forearms when lying? B. Does he hold his head up steadily while on his stomach?	A. Are his hands usually open at rest? B. Does he pull at his clothing?
months	A. Does he lift his head when lying on his back? B. Does he roll from back to front?	A. Does he transfer a toy from one hand to the other? B. Does he pick up small objects?
months	A. Does he sit for long periods without support? B. Does he pull up on furniture?	A. Does he pick up objects with his thumb and one finger? B. Does he finger-feed any foods?
months	A. Is he walking (alone or with hand held)? B. Does he pivot when sitting?	A. Does he throw toys (objects)? B. Does he give you toys (let go) easily?
months	A. Does he walk upstairs with help? B. Can he throw a toy while standing without falling?	A. Does he turn book pages (2 or 3 at a time)? B. Does he fill spoon and feed self?
years	A. Does he run well without falling? B. Does he walk up and down stairs alone?	A. Does he turn book pages one at a time? B. Does he remove his own shoes, pants?
years	A. Does he jump, getting both feet off the floor? B. Does he throw a ball overhand?	A. Does he unbutton any buttons? B. Does he hold a pencil or crayon adult fashion?
years	A. Does he pedal a tricycle? B. Does he alternate feet (one stair per step) going upstairs?	A. Does he dry his hands (if reminded)? B. Does he dress and undress fully including front buttons?
years	A. Does he attempt to hop or skip? B. Does he alternate feet going downstairs?	A. Does he button clothes fully? B. Does he catch a ball?
years	A. Does he skip, alternating feet? B. Does he jump rope or jump over low obstacles?	A. Does he tie his own shoes? B. Does he spread with a knife?

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CONTINUATION FROM INSIDE FRONT COVER . . .

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